Interdisciplinary Care for the Child and Youth with Complex Medical Needs

Ingrid Larson BA, MSN, MBA, RN, APRN, CPNP
Director – Beacon Program
Children’s Mercy
Kansas City, MO

August 2, 2014
Disclosure Statement

• I have no actual or potential conflict of interest in relation to this program.
Objectives

• The learner will be able to define Children and Youth with Special Health Care Needs (CYSHCN) and the need for this population

• The learner will be able to describe the Patient Centered Medical Home Model
CYSHCN: Definition

• The share of children under age 18 who are at increased risk of a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally.

Source: http://mchb.hrsa.gov/cshcn05/
CYSHCN: Definition

- The parent is asked the following 5 questions:
  - Does the child currently need prescription medications?
  - Does the child need more medical care, mental health care, or educational services than his or her peers?
  - Is the child limited in his or her ability to do things?
  - Does the child need physical, occupational, or speech therapy?
  - Does the child have an emotional, developmental, or behavioral problem?
- Rules: the condition is expected to last for 12 months or more and the condition is due to a medical, behavioral, or other health condition.
Very inclusive definition

• This definition means that many, many children will qualify as CYSHCN
• Not as simple as you might think...
• Case Examples:
  – Case 1: Sheila, a 15 year old
  – Case 2: Michelle, a 17 year old
  – Case 3: Billy, a 18 month old
Case 1

• Sheila is a 15 yo with spastic quadriplegia, seizures that are difficult to control, trach and vent, developmental delays, severe osteoporosis with a history of multiple fractures. She has a g-tube and takes nothing by mouth. She is followed by Rehab, Neurology, Nephrology and Orthopedics. She also receives nutrition visits, OT and PT. She has an IEP. She needs orders routinely for supplies for tube feedings, diapers, medications, and other durable medical equipment.
Is Sheila complex?

• I vote yes!
• Sheila’s parents need support for long-term transitioning planning, working with state agencies for disability hearings and waivers and working with state agencies for group home placement as the burden of care increases with age.
• She definitely needs help with coordination!
Case 2

- Michelle is a 17 yo with Down Syndrome. She receives routine screening for her thyroid, x-rays for instability in her neck and does not have a heart defect. She follows in Down Syndrome clinic. She is in mainstream classrooms, eats by mouth, has bowel and bladder control and has a job.
Is Michelle complex?

• I vote no!
• She has an IEP. She may need therapies and will need routine evaluations.
• She will need routine vision and hearing screenings and routine nutrition visits.
• She may need to go to Neurology if seizures develop or may need an evaluation for sleep apnea or ear tubes due to small canals.
Case 3

• Billy is an 18 month old with severe eczema, reactive airway disease (had RSV) and chronic otitis media with effusion. He has been admitted to the hospital due to the severity of his skin condition and for respiratory issues twice in the past three months. He is on multiple medications. He follows with Dermatology, Allergy and ENT.
Is Billy complex?

• I vote yes!
• His conditions are chronic and impair his daily life functions
• He has been hospitalized and likely has also had multiple ER visits.
• Absolutely needs help establishing better control of his conditions and coordinating care.
• It’s not a clear definition.
• Think about the coordination within the care of the child, not the specific diagnosis.
• Think about their needs and what help them be the most successful in daily activities.
• If the needs are above that of a typical child, he or she might be a CYSHCN.
Approximately 40,000 CYSHCN in the United States, or 13% of children, have a special health care need.

Approximately 1 out of 5 homes in the United States has a child or youth with special health care needs.

This does not include children at risk for a chronic condition.

CYSHCN across U.S.

CYSHCN : MO Statistics

In Missouri the number of CYSHCN are increasing and are at the national average as of 2011 – 2012 (20%):

- In 2011 – 2012 was 20%
- In 2007 was 21%
- In 2005 - 2006 was 16%
- In 2001 was 15%

CYSHCN : MO Statistics

• National CYSHCN Survey Core Outcomes:
  – Parents are partners and are satisfied with the care they receive  MO 64.1% US 57.4%
  – Coordinated comprehensive care within a medical home MO 51.8% US 47.1%
  – Services are organized in useful way MO 90.1% US 89.1%
  – Appropriate transition care MO 54.4% US 41.2%

Source: http://mchb.hrsa.gov/cshcn05/MI/NSCSHCN.pdf
<table>
<thead>
<tr>
<th>Indicator</th>
<th>State %</th>
<th>National %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child Health</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CSHCN whose conditions affect their activities usually, always, or a great deal</td>
<td>19.5</td>
<td>24.0</td>
</tr>
<tr>
<td>CSHCN with 11 or more days of school absences due to illness</td>
<td>12.8</td>
<td>14.3</td>
</tr>
<tr>
<td><strong>Health Insurance Coverage</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CSHCN without insurance at some point in the past year</td>
<td>6.3</td>
<td>8.8</td>
</tr>
<tr>
<td>CSHCN without insurance at time of survey</td>
<td>3.1</td>
<td>3.5</td>
</tr>
<tr>
<td>Currently insured CSHCN whose insurance is inadequate</td>
<td>31.0</td>
<td>33.1</td>
</tr>
<tr>
<td><strong>Access to Care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CSHCN with any unmet need for specific health care services</td>
<td>14.6</td>
<td>16.1</td>
</tr>
<tr>
<td>CSHCN with any unmet need for family support services</td>
<td>3.1</td>
<td>4.9</td>
</tr>
<tr>
<td>CSHCN needing a referral who have difficulty getting it</td>
<td>14.3</td>
<td>21.1</td>
</tr>
<tr>
<td>CSHCN without a usual source of care when sick (or who rely on the emergency room)</td>
<td>7.9</td>
<td>5.7</td>
</tr>
<tr>
<td>CSHCN without any personal doctor or nurse</td>
<td>5.6</td>
<td>6.5</td>
</tr>
<tr>
<td><strong>Family-Centered Care</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CSHCN without family-centered care</td>
<td>27.8</td>
<td>34.5</td>
</tr>
<tr>
<td><strong>Impact on Family</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CSHCN whose families pay $1,000 or more out of pocket in medical expenses per year for the child</td>
<td>19.4</td>
<td>20.0</td>
</tr>
<tr>
<td>CSHCN whose conditions cause financial problems for the family</td>
<td>15.6</td>
<td>18.1</td>
</tr>
<tr>
<td>CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care</td>
<td>9.0</td>
<td>9.7</td>
</tr>
<tr>
<td>CSHCN whose conditions cause family members to cut back or stop working</td>
<td>19.5</td>
<td>23.8</td>
</tr>
</tbody>
</table>
CYSHCN: Financial Reality

• CYSHCN alone account for 80% of pediatric health care expenditures

• Annual cost of providing medical care to CYSHCN
  - Hospitalization: 61%
  - Specialists: 14%
  - Durable medical equipment: 5%
  - Primary care: 5%
  - Other: 15%

Source: Health Partners/Institute for Health and Disability
CYSHCN: Reality for Families

- 39.5% indicate their child’s or youth’s condition impacts family’s financial situation
- 13.5% say they spend 11+ hours/wk coordinating care for their child or youth
- 24.9% indicate families cut back on work due to child’s or youth’s condition
- 28.5% indicate families stop working due to child’s or youth’s condition

Source: Health Partners/Institute for Health and Disability
CYSHCN: Reality for Providers

- **Time**
  - Clinical evaluation
  - Record reviews
  - Patient/Family counseling and education
  - Coordination of services

- **Clinic Environment / Resources**
  - Physical clinic space / accessibility
  - Staffing / personnel comfort and training

- **Electronic resources and documentation**

- **Unfamiliarity with the patient / family**

- **Reimbursement**
CYSHCN: Reality for Schools Nurses

• Time / Information
  - School nurses have to triage and deal with actual medical emergencies, then health urgencies, then day to day illness and injuries, then parent / teacher information exchange, paperwork, all while keeping everyone's medication and treatment routines on schedule.

• Classroom Environment / System
  - Children have seizures right in the middle of a routine tube feeding, being squeezed in between 55 lunch medications, on the other end of the building from where their Clonazepam and Diastat are being stored.

• Training
  - Classroom support staff
  - Bus staff
CYSHCN: The Need

• A way to care for CYSHCN that is comprehensive and coordinated
• That involves all members of the child’s healthcare team
• And is supportive of the family’s needs
How do we answer the need of CYSHCN in the face of healthcare reform?
Institute for Health Improvement Triple Aim

- Improving the patient experience of care (including quality and satisfaction)
- Improving the health of populations
- Reducing the per capita cost of health care

Source: http://www.ihi.org/offerings/Initiatives/TripleAim/Pages/default.aspx
Increase Value

• Improve clinical outcomes = QUALITY
  • Decrease ER visits
  • Decrease hospital admissions
  • Increase preventative screenings, quality measures

• Improve reimbursement and reduce COSTS

• Higher satisfaction for patient, providers and staff

• So... how do we accomplish that...?
In response to health care reform, the Patient Centered Medical Home (PCMH) has been presented as the answer to the delivery of primary care.
PCMH : Why Now?

• Research over past 3 decades show that CYSHCN and their families have substantial unmet healthcare needs.
• CYSHCN and their families require a higher level of care and coordination of services for.
• Substantial evidence that CYSHCN benefit from clinical services that are provided within a Medical Home.

Sources: Cooley WC. Developing primary care medical homes for CSHCN. Presented at: Institute for Leaders in State Title V CSCHN Programs; May 19, 2003; Baltimore, MD

PCMH Support

- Importance of the Medical Home has been recognized by:
  - Legislators/policymakers and public health agencies
  - 15 states have enacted legislation to create or encourage the creation of medical homes for children. Some target CSHCN while others recognize the importance of a medical home for all children
- 2002 AAP NCMHI Project Advisory Committee Policy Statement
- 2004 AAFP Future of Family Medicine project
- 2006 American College of Physicians primary care report
- Healthy People 2010 and 2020 – 2 goals and 28 focus areas
  - Comprehensive set of national health objectives for the decade
  - Increase quality and years of healthy life
  - Eliminate Health Disparities
- Maternal and Child Health Bureau Core Objectives
### PCMH Professional Support

- American Academy of Family Practice
- American Academy of Pediatrics
- American Osteopathic Association
- American College of Physicians
- American Academy of Hospice and Palliative Medicine
- American Academy of Neurology
- American College of Cardiology
- American College of Chest Physicians
- American College of Occupational and Environmental Medicine
- Infectious Diseases Society of America
- Society for Adolescent Medicine
- Society of Critical Care Medicine
- American College of Osteopathic Family Physicians
- American College of Osteopathic Internists
- American Geriatrics Society
- American Medical Association
- American Medical Directors Association
- American Society of Addiction Medicine
- American Society of Clinical Oncology
- Association of Professors of Medicine
- Association of Program Directors in Internal Medicine
- Clerkship Directors in Internal Medicine
- American Nurses Association
- The National Association of Pediatric Nurse Practitioners
- American Association of Critical-Care Nurses
- Society of Pediatric Nursing
What is a PCMH?

A House Is Not A Home: Keeping Patients At The Center Of Practice Redesign

The patient-centered medical home could well be a transformative innovation—for some practices now, but for many others only in the long run.

by Robert A. Berenson, Terry Hammons, David N. Gans, Stephen Zuckerman, Katie Merrell, William S. Underwood, and Aimee F. Williams

ABSTRACT: The "patient-centered medical home" has been promoted as an enhanced model of primary care. Based on a literature review and interviews with practicing physicians, we find that medical home advocates and physicians have somewhat different, as though not necessarily inconsistent, expectations of what the medical home should accomplish—focusing on care management for patients with chronic conditions. As the medical home concept is further developed, it will be important to reevaluate the redress of practices at the expense of patient-centered care, which is the hallmark of excellent primary care. [J Health Polit Pol Sci. 2009;3, 5:3187-3210: 10.1377/hps.2007.0215]

THE PATIENT-CENTERED MEDICAL HOME (PCMH) is the newest idea being promoted as a transformative health system innovation. Proponents believe that it will improve the quality of and patient experience with care and alter the trajectory of inflationary health care spending. The PCMH has been proposed by four primary care physician specialty societies; has been endorsed by a range of purchasers, labor, and consumer organizations, including IBM, Merck and Company, the ERISA Industry Committee, and AARP; and is being tested in demonstrations by major public and private health plans, including Medicare, various Blue Cross and Blue Shield plans, UnitedHealthcare, and Aetna. The medical

Robert Berenson (berenson@jurist.org) is a senior fellow at the Urban Institute in Washington, DC. Terry Hammons is a senior fellow at the National Group Management Association and the McGraw Center for Research in England, Colorado. David Gans is a vice president of practice management resources at the NGMA. Stephen Zuckerman is principal research associate at the Urban Institute's Health Policy Center. Katrina Herson is a senior research scientist at Social and Scientific Systems in Silver Spring, Maryland. William Underwood is an associate at the American College of Physicians, Center for Practice Innovation, in Washington, DC. Aimee Williams is a research associate at the Urban Institute's Health Policy Center.

HEALTH AFFAIRS - Volume 27, Number 5
DOI: 10.1377/hps.2007.0215 ©2013 Health Affairs, Inc.
PCMH Concept

• An approach to providing health care services in a high-quality, comprehensive, and cost-effective manner

• Provision of care through a primary care provider through partnership with other health care professionals and the family

• Acts in CYSHCN’s best interest to achieve maximum family potential
PCMH Definition

• A team-based model of care led by a personal provider who provides continuous and coordinated care throughout a patient's lifetime to maximize health outcomes

• Responsible for providing for all of a patient’s health care needs or appropriately arranging care with other qualified professionals. This includes the provision of preventive services, treatment of acute and chronic illness, and assistance with end-of-life issues

• A model of practice in which a team of health professionals, coordinated by a personal provider, works collaboratively to provide high levels of care, access and communication, care coordination and integration, and care quality and safety.

PCMH Model

- Enhanced Access
- Empanelment / Population Management
- Team-based Healing Relationships
- Patient-Centered Interactions
- Organized, Evidence Based Care
- QI (Quality Improvement)
- Care Coordination

PCMH Model represents a patient-centered medical home model that emphasizes coordinated, evidence-based care, patient-centered interactions, team-based healing relationships, and enhanced access.
PCMH Building Blocks

- Personal provider
- Provider directed practice
- Whole person orientation
- Coordinated care
- Quality and safety
- Enhance access
- Payment reform

The Foundation

• A partnership between the family and the child’s primary health care professional – a relationship of mutual responsibility and trust
PCMH Participants

- Primary care provider
- Family
- Child / youth
- Nurses and allied health care professionals
- Family’s community
- Pediatric office staff
- If necessary, pediatric sub-specialists
PCMH Transformation

Current Care Model
Reactive
Provider Centered
Fragmented
Address reason for visit only
My patients are those that have an appointment today
Patients are responsible to coordinate their own care

PCMH Model
Proactive
Patient Centered
Coordinated
Care determined by proactive plan
Our patients are those that are registered in our medical home
A prepared team coordinates all patient’s care
PCMH Model

- Care is coordinated by a team of health care professionals
- Care is coordinated and not episodic
- Directed by a well-trained provider (who is known to the child and family) providing primary care
- The PCP manages and facilitates essentially all aspects of pediatric care
- Long-term healing or holistic relationship instead of illness based encounters
PCMH Recognition

- Patient-Centered Medical Home Recognized Practice 2011
- Keep Calm and Become a Medical Home
- Accreditation Association for Ambulatory Health Care
- The Joint Commission: Helping Health Care Organizations Help Patients
NCQA PCMH Standards 2011

Core Components
- Enhance Access and Continuity
- Identify and Manage Patient Populations
- Plan and Manage Care
- Provide Self-Care and Community Support
- Track and Coordinate Care
- Measure and Improve Performance

Must Pass Components
- Access during office hours
- Use data for population management
- Care management
- Support self-care process
- Track referrals and follow-up
- Implement continuous quality improvement
NCQA PCMH Scoring

**PCMH Scoring**
6 standards = 100 points
6 Must Pass elements

Must Pass elements require a ≥ 50% performance level to pass

<table>
<thead>
<tr>
<th>Level of Qualifying</th>
<th>Points</th>
<th>Must Pass Elements at 50% Performance Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 3</td>
<td>85 - 100</td>
<td>6 of 6</td>
</tr>
<tr>
<td>Level 2</td>
<td>60 - 84</td>
<td>6 of 6</td>
</tr>
<tr>
<td>Level 1</td>
<td>35 - 59</td>
<td>6 of 6</td>
</tr>
<tr>
<td>Not Recognized</td>
<td>0 - 34</td>
<td>&lt; 6</td>
</tr>
</tbody>
</table>

Practices with a numeric score of 0 to 34 points and/or achieve less than 6 “Must Pass” Elements are not Recognized.
Who’s already a NCQA PCMH
4,937 sites & 23,396 clinicians as of 10/31/2012

Source: Analysis by the National Committee for Quality Assurance, Oct. 2012.
CYSHCN receiving care in a PCMH

2009/10 National Survey of Children with Special Health Care Needs

Nationwide:
43.0% of CSHCN met outcome
State Range:
34.2-50.7

State Ranking
- Higher-Better Performance
  - Significantly higher than U.S.
  - Higher than U.S. but not significant
  - Lower than U.S. but not significant
  - Significantly lower than U.S.
  - Statistical significance: p < .05
PCMH Change Process

• Empanelment

• Care Teams: providers, nurses, care assistants, schedulers, respiratory therapists, social workers, dietitians

• Changed schedules / increased access

• Pre-visit planning / standing orders

• Data monitoring: Clinically important conditions (preventive, acute, cost)

• Follow-up phone calls: ER / UCC and inpatient

• Coordination with specialists and other HC providers
Patients must have a primary care provider (PCP)

- Each patient must have an ongoing relationship with a primary care provider who will provide or coordinate continuous, comprehensive care. This is achieved through *empanelment*.
PCP Responsibility

• The personal provider leads a team of individuals at the practice level who collectively take responsibility for the ongoing care of their patients.

• Personal provider is responsible for providing for all the patient’s health care needs or taking responsibility for appropriately arranging care with other qualified professionals.

• This includes care for all stages of life; acute care; chronic care; preventive services; and end of life care.
Patient Centered Care

- Patient-centered orientation- considering unique needs, cultures, values and preferences
- Self Management Support (SMS) -Developing plans of care with the patient, not for the patient
- Utilizing Patient education materials
- All staff working at their capacity to engage with patient effectively
Work is distributed across a team

• Care is facilitated by a provider led medical team with each member functioning at their highest level according to credentials and competencies.
Schedule Assessment

• Multiple providers are on a team and the cover for each other’s patients
• Each care team needs to provide for access each half day, 5 days per week
• Same day access for acute and routine visits to accommodate the family
Team based healing relationships

• Care determined by proactive plan
• Meet patients needs
• Address chronic disease at every visit
• Staff work flow-
  – Pre-visit Planning/Huddles
• Working at the top of license
Coordinated Care

• Integrated across all elements of the complex health care system and the patient’s community

• Facilitated by registries, information technology, health information exchange, Quality and Safety

“I just want my doctors to talk to each other”
Clinically important conditions

- The practice must measure at least:
  - 3 Preventive Care Measures
  - 2 Chronic or Acute Measures
  - 2 Measures that Affect the Cost of Healthcare

- Obtain patient experience feedback from families

- Set Goals and Improve at least one measure from each of these groups

- Involve families in the improvement process
Evidence Based Care

- Clinical Practice Guidelines (CPG’s) for clinically important conditions
- Educating providers—everyone on the same page
  - Consistent message for patients
  - Standardized workflow can create more satisfaction for staff
  - Performance monitoring
  - Improved outcomes
# Traditional Disease Management to Medical Home

## Disease Management
- Population focused
- Disease managers
- Remote patient activation
- Change *patients* & providers

## PCMH
- Office practice focused
- Multidisciplinary teams
- Local patient activation
- Change *providers* & patients
Outcomes are Improved

• By measuring and proactively contacting patients, conditions are better measured.
• Same day access helps prevent ER visits and inpatient stays.
• Lower DNKA rate
• Increased continuity
• Increased patient and provider satisfaction
Definition of Quality Care for CYSHCN

- Contains components of a PCMH, providing and coordinating comprehensive care for CYSHCN
- Patient / caregiver and provider satisfaction determined with surveys and improved
- Improved patient outcomes are a result
Definition of Quality Care for CYSHCN

- Ensuring appropriate preventive care
- Ensuring follow-up occurs with all specialists at the recommended interval
- Ensuring that the family has the necessary support to care for the child and themselves (home health, counseling, IEP, community resources)
- Ensuring that the PCP is the primary coordinator and knows about all aspects of the child’s care.
• Clinical encounters and patient management may result in sub-optimal care, inefficient management and frustrated families and health care providers.

• A patient centered medical home will help ensure this does not occur for all CYSHCN.
Resource for more information about PCMH

Educating Medical Students and Residents on Medical Home

Medical Home Resident Education Initiative Work Group (REIWG)
- Medical Home Resident Education Initiative Work Group (REIWG)
- AAP Community Pediatrics Training Initiative (CPTI)
- Residency Education in Community-based Pediatrics and Medical Home

Medical Home Resident Education Initiative Work Group (REIWG)
The Medical Home REIWG was convened under the auspices of the National Center for Medical Home Implementation to assess and address the needs in the area of resident education related to medical home for all children and youth, including children with special healthcare needs (CShCN), care coordination, and family-centered care, respectively. The overarching goal of this initiative is to provide direction, tools, and resources to residency program directors, faculty, and others in their efforts to educate trainees regarding the core tenets of medical home. This includes the promulgation of suggested strategies for medical home implementation at the hospital, practice, and community levels. An initial focus of the initiative is the development of activities related to medical home implementation to be organized according to the related Accreditation Council for Graduate Medical Education (ACGME) Core Competencies.

Work Group Roster
- Renee Turchi, MD, MPH, FAAP, Chairperson
- Molly Cole
- Garry Gardner, MD, FAAP
- Matthew Garber, MD, FAAP
- Marca Jackson, PhD (Instructional Designer)
Conclusion

• A need exists for excellent coordination of care for a CYSHCN in all settings.

• The PCMH is proposed as the answer to this need

• We will need to find ways to facilitate communication among all the different settings of the CYSHCN’s life.
Questions and Discussion